

**Public Attitudes toward Advances in Genetics, Genetic Privacy and the Potential  
Misuse of Genetic Information**

*Christy White*

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MS. BERRY: Is Christy here? Christy White is principal and co-founder of Cogent Research Corporation, a strategic research marketing firm, and she will be presenting a report on Cogent's research findings on public attitudes about the privacy and misuse of genetic information, the role of the government in protecting that information, and government access to genetic information. A copy of Ms. White's biosketch can be found in the briefing book.

MS. WHITE: Thank you for having us here today. We're honored to be able to speak to you about this topic that we believe is very important, and in fact have been tracking for a few years now, and plan to do so into the future.

Cogent is a market research firm. We're in Cambridge, Mass. We've been around for around 10 years. The majority of the work that we do is proprietary in nature. We do a lot of work with industry, and a lot of work with the government as well. We saw this as an important issue to start tracking on behalf of both populations.

The objective of the research was to provide a very comprehensive and actionable assessment of where American views were at that point in time, a snapshot toward genomics so that we could help inform industry strategy and policy development.

The study itself looks at four main areas. Awareness, favorability, and interest towards genomics. So we start out very basically trying to understand what they know about genes in general, and the relationship between genes and health. Also what they know about genomics in particular, what they think about it on a general level for the population as a whole, and how interested they are on a personal level for themselves.

The study also looks at the specific catalysts and barriers to adoption and usage, trying to understand what are the perceived benefits and drawbacks, what are their fears and hopes for genomics for them, and for the public as a whole.

We also look at lot at preferences for delivery. I won't spend any time on that today. That's my industry speech. But we look a lot, and if anyone is interested in that, we do have some very interesting data on what will maximize consumer interest in terms of how they want to get the information, who they want to be involved in the decision whether or not to have a test or not, how they want the information delivered to them, and how they want the information stored. I will touch on that to the extent that it relates to the topic here today.

Lastly, we look at messaging and communication. So using some of the information that we know from qualitative research, I'm going to be speaking to the quant study here. What are some of the potential messages and things that we might say to consumers to alleviate some of the fears that they have, or address some of the concerns.

The methodology for this study was a web-based study. We looked at U.S. adults, 18 plus. This profile of the sample is representative of the U.S. population on key socioeconomic variables, ethnicity, region, and gender. These are back to the 2003 projections, that's the data that we use for comparisons there.

SACGHS Meeting Transcript  
October 19-20, 2005

We conducted the data last January, in the middle of January. We're actually getting ready to run the study again, we'll probably run it toward the end of January this year for our third year. This survey, as I mentioned earlier, the majority of what we do is proprietary in nature. This study was ours, so we had full control over it. We got a little out of control, we have 205 questions. There is a lot to know, explore, and look into on this topic.

We talked to a total of 1,000 consumers, which gives us a sampling of plus or minus three at the mid-range. We looked at a wide variety, a good chunk of those questions, probably around 40 of them are demographic questions. We really wanted to be able to tease out what are some of the differences by some of these different key demographics. We also conducted a robust psychographic segmentation model. So if we clump people together by their belief systems, as opposed to a demographic like age, can we understand or tease out some differences in the population in terms of what's happening.

There are a few things that we're going to do differently next year when we run this. There are a couple of areas we're going to look into, and this is based upon some meetings I've had both with government and industry. We're going to delve more deeply into people's awareness and usage of Internet-based products. I know this is something the CDC is very interested in in particular.

We'll also be looking more completely at workplace discrimination. We do touch on that here. Our focus was mostly on insurance and government this past year, but we will be looking more closely at workplace discrimination.

Also awareness of the current legislation and protections that are in place. We want to understand, you know, do people know what protections there are, what do they think of those protections, and what would their hopes be for where those protections might go? What would actually have an impact on that?

So that data, as I imagine, would be of interest to this committee, would be available I'm guessing early February of next year. We'd be happy to come back and talk about that.

So I'm going to walk through just a few key findings from the study, probably around 40 of the 200 questions. So it will give you a good picture, but clearly there's a lot more here.

The first basic thing we want to know is are consumers even aware of the issue. We asked them how much they have heard or read about using individual genetic information to understand and optimize health. You can see that awareness is very broad, three-quarters of Americans saying that they have heard at least something about this issue.

When we delve a little bit deeper into it, we understand that it is really not a very sophisticated understanding. Only 4 percent of Americans are telling us that they have heard a lot, one-third of those who say they have heard something can't recall any specific details. Of those who can recall those details, they are mostly telling us that they understand there is a relationship between genes and health, and not specifically how they can use that genetic information to potentially alter or improve their health.

There are a few, however, that are getting at least to some extent, a more sophisticated understanding of what's happening. They tell us things like genes can be manipulated from a health benefit, they can lead to early diagnosis and detection, they can help find cures for diseases, and then of course can be used in the prenatal stage. So there are some consumers that are at that more sophisticated level of understanding.

We do know from qualitative research that this is classic, this is what they'll say back to us. It is very easy to get them to make the leap. So although everyone is aware and they're just aware in general about the relationship, it is not difficult to get them to make that leap almost on their own of how they could start harnessing the power of that information for themselves.

When we look specifically at interest around prescription drugs, making informed choices about prescription drugs, awareness drops to 43 percent. So we've got 75 percent getting that specific level of just the general level of understanding, but 43 percent with prescription drugs. That is still actually not a very low number.

So what are their general attitudes? Their attitudes are highly favorable. You can see in general when we asked them, "In general, how favorable are you toward the idea of using genetic information to understand and optimize health?" You see more than half of Americans are saying that they're favorable.

This is actually quite a high number. We might expect to see a bell curve here with the majority of people being in that sort of middle level, particularly since they don't fully understand it yet. But we see that there are a lot of people that are very excited, and they see a lot of promise in genomics in general.

They are also as excited about it on a personal level. So when we asked them, "How interested would you be in using your genetic information for the purpose of understanding and optimizing your health?" you can see that that interest is still quite high.

So how does that play out for personalized medicine in particular? Fifty-eight percent of the U.S. population, or adults, are saying that they're favorable towards using their individual information to make informed choices about prescription drugs, and 51 percent are interested in using that information for themselves personally.

What we did at this point in the survey was we delved more deeply, so we're trying now to give them this understanding of how they can use the information. There are specific ways in which they might use their genetic information when it comes to personalized medicine or prescription medicine in particular.

We looked at three areas. Efficacy, so which drugs would be most effective in your body, safety, whether they would have an adverse reaction to the drug, and prevention, whether they would take the drug preventively.

Probably not surprisingly, safety -- these are all very high and quite close, but safety is clearly the one that they're most interested in in terms of the usage. But very close behind that comes efficacy, and not surprisingly, the third would be preventative or proactive usage of prescription medication.

So I think what these slides do is they present a picture for us that consumers, they're ready. They're interested in this, they can easily be brought along. They are interested anyway, and they can easily be brought around to understanding how they can use it. When you express it to them, they say yes, I'm interested in doing that on a personal level. What we'll look at now is the how, what it is that needs to be in place for them to actually do this.

So from a variety of data, both qualitative and quantitative, and a variety of different types of questions, we see that interest is solution-driven. By that, what we mean is that they are

interested in reducing their risk of specific diseases. We asked other questions like would you want to do this just to get a genetic profile for yourself and your family, and for posterity sake, would they be interested in doing it for health benefits such as sleep, things like that.

Really where the interest is greatest, and the interest is great across the board, and that's one of the things I should have mentioned earlier. There is not one key demographic group where interest drops below 40 percent. So unlike other areas, or even when we're working with industry, we go and say these are the people to target. It's high income, it's this, it's that.

In this particular case, interest is so broad that there are opportunities for all Americans in terms of products that could be created, and they are taking advantage of them. But in particular, they want to focus specifically on reducing diseases.

They also are most interested in finding out information if they are certain to experience that, and I know that may be something that's very hard to deliver on, but their concern is that they don't want information if they can't do anything about it. Again, they are still interested in that, but they're more interested if you can tell them they're certain to experience that.

And lastly, they want to know that there is some treatment. So tell me I'm at risk for this disease, I'm definitely going to get it, and tell me that there is something you can do for me.

There are three key things that we believe are critical to long term and continued acceptance of genomics. They relate to privacy concerns, emotional consequences, and moral issues. There is a very high correlation between these three variables and favorability and interest.

The privacy concerns are there at the bottom, because it is sort of the barrier that we have to get through to even be talking with them. It's a big concern for them, and it's something that we need to address and deal with. Right now they're on the fence about whether or not there is an issue, and we'll talk about that.

Ethics are at the top because I think they have the potential to topple this whole thing ultimately. We'll talk about that, too. So down at the bottom, I think what privacy can result in for Americans is limited usage of genomics. What the ethical issues can do to this is that there would be no usage of genomics.

We looked at privacy from three issues, as I mentioned earlier. Employers, government, and insurance, mostly focusing on insurance and government this time around. But from both qualitative and quantitative, these are the dominant issues that come into play when you ask them about things that might limit their usage of genomics.

So we'll start with the moral issues. What we're showing here are the top two boxes in the blue for agreement with a few statements, which I'll read to you. What we have done here is we have thrown in those people in the midpoint, the three on the five point scale. We're calling those the people who are the fence sitters.

So when you look at some of these statements that relate to ethics and moral issues in general, you can see that close to 50 percent of the public either agree with some of these statements, or they're on the fence. They have the potential to be swayed to agree with some of these arguments.

SACGHS Meeting Transcript  
October 19-20, 2005

The first one, "Some of the recent advancements surrounding the use of genetic testing make me uncomfortable from a moral standpoint." So about one-fourth agree with that, and 55 percent total, we include the fence sitters.

"Meddling with our genes and DNA is trying to play God. Scientists, researchers, and doctors should stay out of it altogether." A little bit less agreement, but still we're getting close to 50 percent when we include the fence sitters.

Lastly, "Genetic testing should be stopped, because it will ultimately lead to cloning or altering human genes." Fifteen percent agree, 45 percent fence sitters.

I think that there are lots of examples of scientific advances that have either been stopped, or at least the public hasn't been able to benefit from them fully because of moral arguments that have been made. This, you can see that these are a minority of people, potentially a vocal minority, and potentially a large percentage of Americans that could be swayed one way or another.

Talking about that middle part of the pyramid now, the emotional costs. So this really relates to the fact that knowing my genetic profile is too great a responsibility, it impacts myself, my spouse, and ultimately my children's lives. So close to one-fourth of Americans are saying they agree with that. Slightly more are saying that it would be depressing to know I was going to get a disease, or too depressing to know I was going to get a disease, particularly if there is nothing I can do about it.

So this is not as big of an issue as privacy, which we'll now move onto, but certainly it is something that needs to be addressed.

Privacy. So 68 percent of Americans are telling us they're concerned, it's a 4 and a 5 on a 5-point scale, about how their personal genetic information would be stored, and who would have access to that information. One-third of all Americans, not just out of that subset, but one-third of all Americans are telling us that their concern would prevent them from having a genetic test. So it's not at a great level yet, but could potentially be an issue.

So trying to understand a little bit about why they are concerned, of course everything we've talked about already, but specifically here, one-third of Americans are saying that they consider the results provided by DNA testing to be more sensitive than results provided by other tests, so there is an understanding there that that information is potentially more dangerous for them specifically if it were to be misused.

Also, about half of Americans say that they are torn on the use of genetics. That gets back to that point I made about the ethics with the fence sitters. But here what they're talking about is the potential benefits are incredible, but the potential for misuse is considerable.

Misuse predominantly means that people are worried, half of the Americans are saying worried that their DNA sample may be used for tests other than the ones that I have authorized. We see this in qualitative all the time when you ask them about their concerns.

This issue that, well, what is going to happen to my DNA, who is going to have access to it, who is going to make sure that no one has access to it? So let's talk about misuse.

Not that this is probably a huge surprise, but there is a lot of concern about insurance companies in particular here. We had put in a few inflammatory statements with the goal of really trying to

tease out who are those people who are concerned about insurance. As you can see, even with a statement like, "Insurance companies will do everything possible to use my genetic information to deny health coverage," 68 percent of Americans agree with that statement.

"Insurance companies will use the information to deny coverage for drugs people need if the genetic profile indicates a low chance of responding." And 60 percent say that their level of interest would decrease if the information became part of their medical record, and was therefore obtainable by insurance companies.

However, they do want insurance companies to pay for these tests. Fifty-three percent say that their interest level would be decreased if the insurance company would not cover the costs of genetic tests.

The role of the government in privacy, as I mentioned, we're going to put in some more questions about this the next time we run this. At this point, what we do know is that Americans do want the government to protect their privacy.

Sixty-four percent say that their interest would be increased on a personal level if they were assured by law that no one could access their DNA information without their consent. What we want to do next time is understand, well, do they think there are protections in place and they don't think they're adequate, or do they not understand there are any protections in place, and what do they think of the current protections that are in place? We'd be happy to work with someone on this committee if they want to look at those specific questions before we field them.

"The government should establish specific laws and regulations to protect the privacy of genetic information." Seventy-one percent are agreeing with that. The majority were on the fence otherwise. There was not a lot of people not agreeing with that.

Similar to what we saw with insurance companies, not trusting them but wanting them to pay for it, we see a similar dynamic here. They want the government to protect their privacy, but they don't want them to have access to their information. Only 24 percent agree the government should create a national database of DNA information for the future health of all Americans, and only 1 percent when given a multiple choice that included a variety of different options selected the government as a place -- who beside you should receive a copy of the results of your genetic test? So only 1 percent of Americans thought that the government should have a copy of that.

These are some of the key learnings that we took away from the research, and some of these frankly have more to do with industry, but I think government certainly can get involved in some of these important issues.

First of all, we believe that there needs to be an effort to deepen American's understanding of genomics. We know there is a positive correlation between awareness and interest. So whatever they're reading so far has been positive, and it's leading them to be interested in this. I think we know that when we draw a connection to how they can actually use it in their lives, they continue to be interested. So I think there's a need to deepen their understanding of how they can use genomics.

There needs to be a focus on diseases where solutions exist, because to my point earlier, if we're telling people about diseases that they're likely to get and there's no solution for it, we're just unnecessarily upsetting them.

SACGHS Meeting Transcript  
October 19-20, 2005

Advocating for privacy protections with limited involvement. So on both levels, protections, government-related and insurance-related with limited involvement from those parties in terms of access to information, and addressing the moral concerns or framing the moral issues in a way that can help people understand how this can benefit them in the long term, and what the ethical benefits are to genomics.

And that is it.